

Exploring Decision-Making and Inequity in Gene Therapy for Alzheimer's Dementia

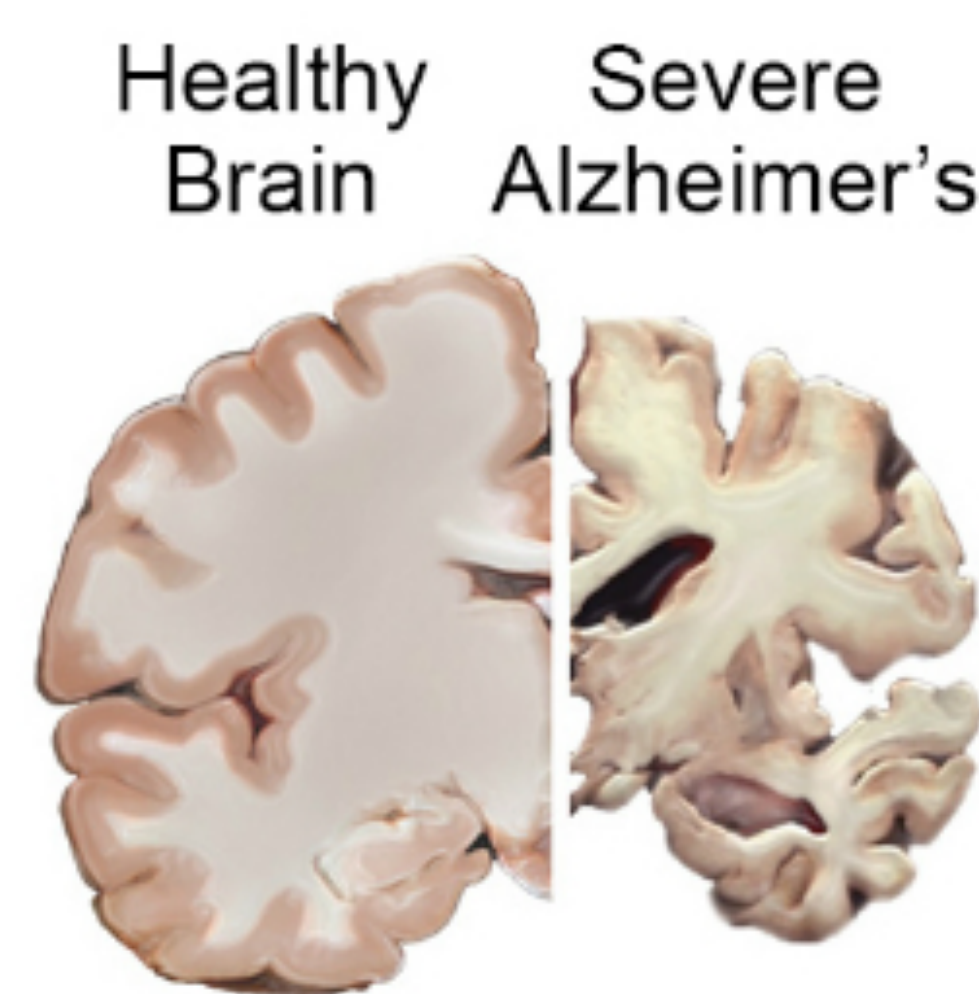
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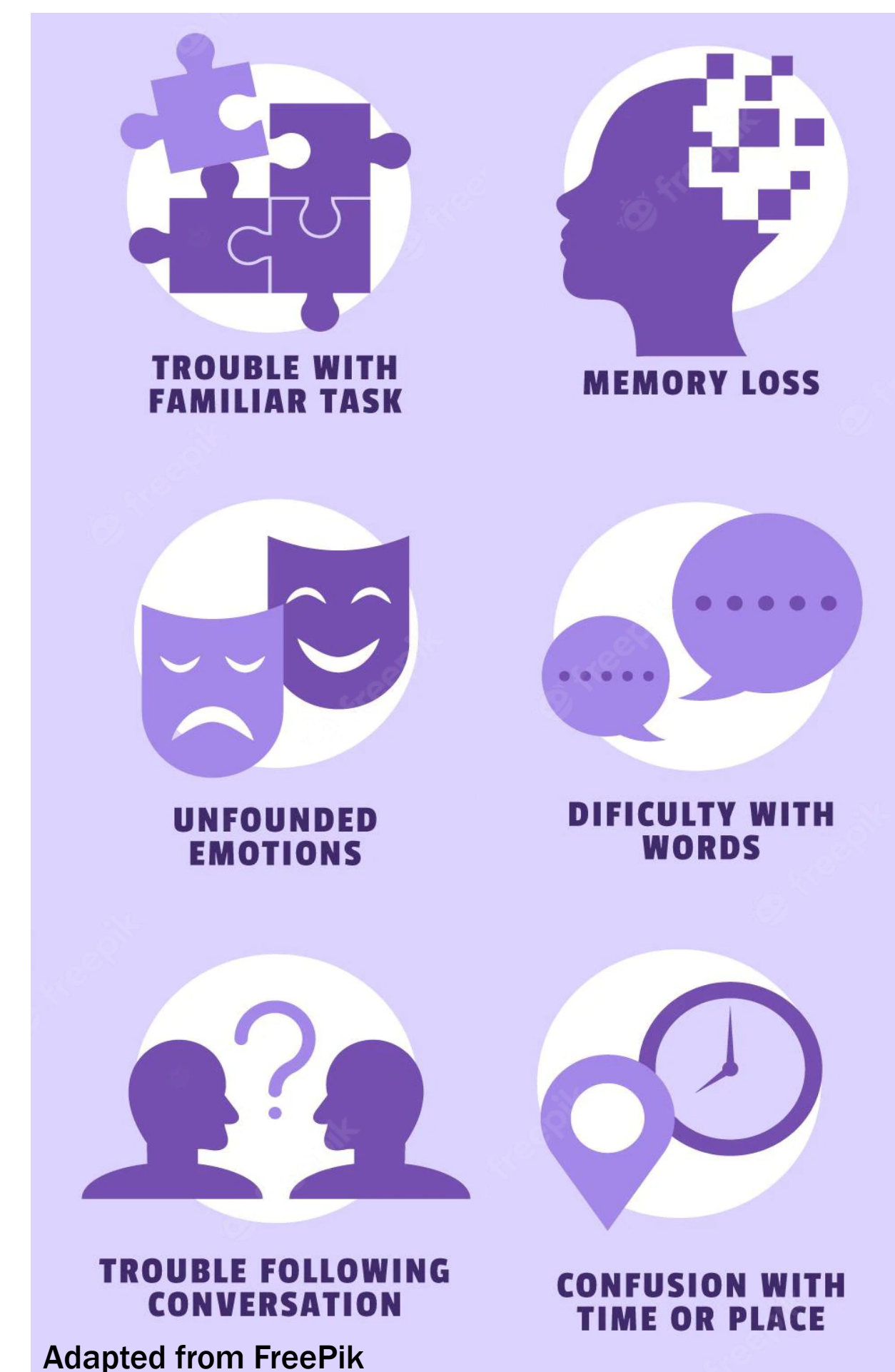
As advanced therapeutics like gene therapy enter clinical trials, we aim to understand clinician and patient knowledge, concerns, and decision-making factors to aid market transition and address inequality.

What is Alzheimer's Disease?

- Neurodegenerative disease
- Affects 6.2 million people in the US, expected to double by 2060
- Minority groups are often diagnosed later than white Americans



Source: NIH.gov



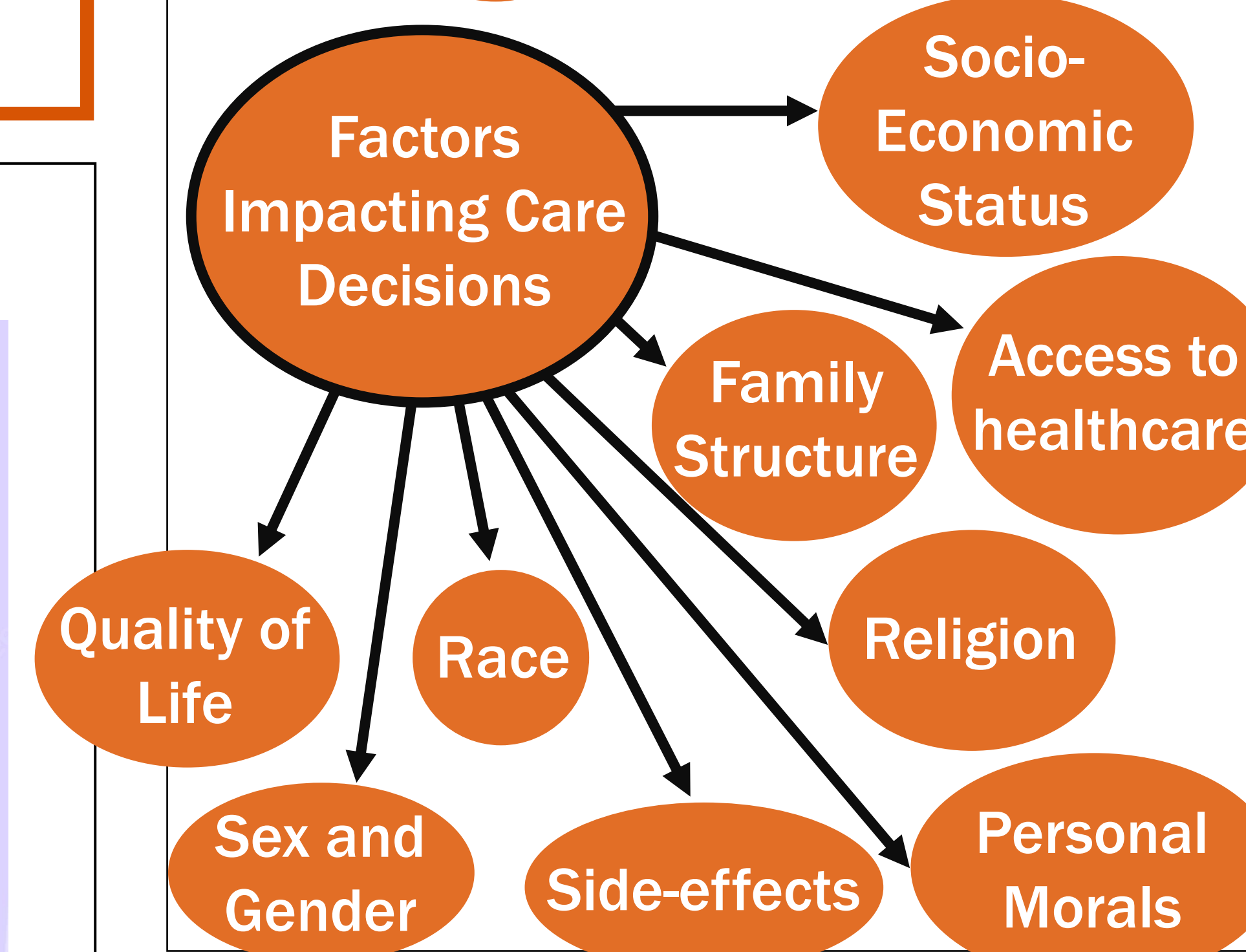
What is Gene Therapy?

Gene therapy is an experimental technique that uses genes to treat or prevent disease

Gene Therapy and Alzheimer's Disease

- 27 trials for Alzheimer's gene therapy on clinicaltrials.gov
- Current AD gene therapy targets include nerve growth factor (NGF) or apolipoprotein E2 (APOE2)

How do dementia patients and caregivers make care decisions?



Clear explanation of risks and benefits is key to informed decision-making.

- Clinicians have limited time with patients
- Most patients have limited scientific context to understand gene therapy
- Can the patient make their own decisions?

"It would be a lot to expect it within the time frame of a primary care visit to be able to start to introduce these topics"

"Providing education to them would be helpful. Sometimes there are some caregivers who like a lot of information."

"Is it cumbersome? Is there going to be a lot of follow up bloodwork or imaging? Um, is it painful? What's the time commitment?"

Questions of inequity

Many elements of decision making are impacted by inequity.

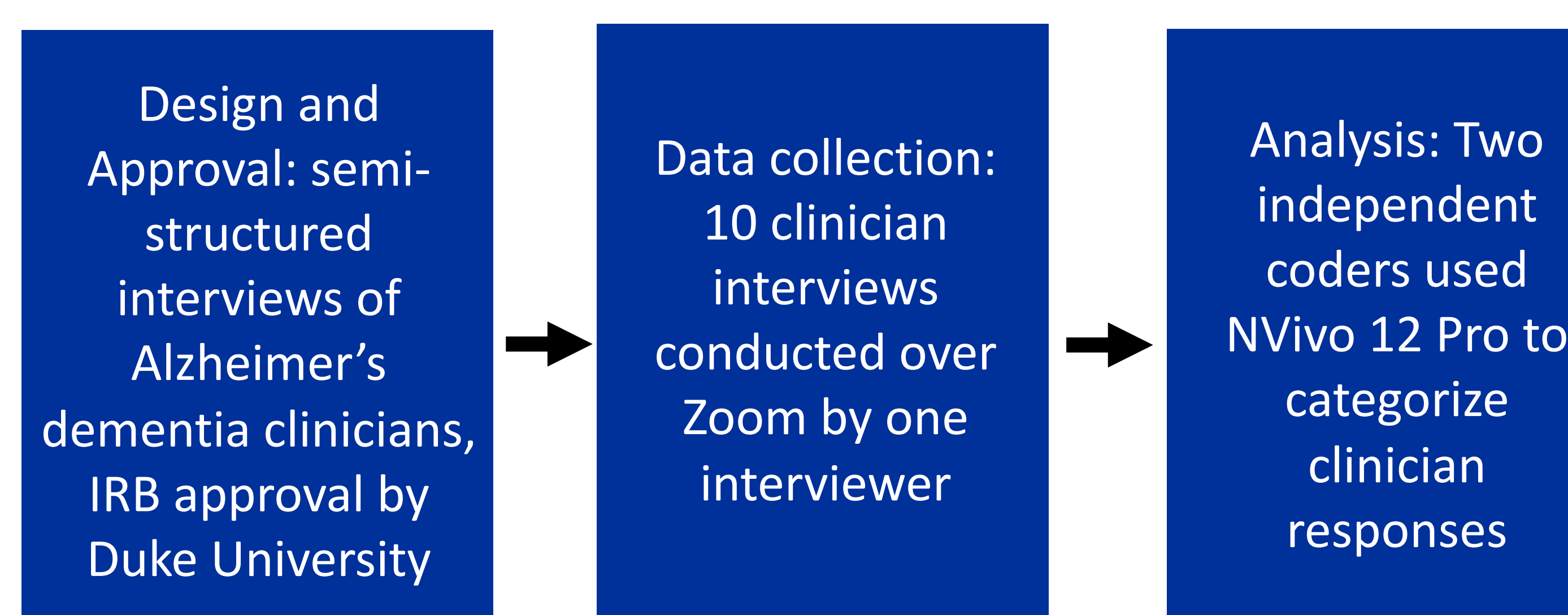
- Socio-economic status—Cost of treatment, time away from work
- Access to healthcare—Does patient have health insurance? What does it cover? Location of treatment clinics and access to transportation
- Education—literacy and numeracy
- Family support—Who brings patient to the doctor? Who provides at-home care?
- Race—Trust in healthcare, doctors, and medical institutions

"Not having family support there to help encourage some to go seek out care [could be a factor]."

"In general, people with poor access to healthcare will wait longer before being seen for anything because it's not, you know, worth the money and the time away from other activities that actually generate money."

"There's a lot of distrust with the healthcare system or providers as well, that would prevent [Black patients] from seeking out care."

Methods



Conclusions

Takeaways

- True informed care centers the patient's personal values and addresses their individual concerns
- Patients are unfamiliar with concepts necessary to understand gene therapy
- Challenges for Inequity**
- Systemic problems do not have fast solutions, highlighting the importance of advanced planning
- Clinicians have limited time

Remaining Questions

- What are the patient and caregiver perspectives on these issues?
- How can gaps in patient and caregiver education be optimally targeted?

Policy Recommendations

- Bring treatment education to patients—Develop educational content for news and social media
- Raise awareness around racial disparities in Alzheimer's disease
- Promote diversity in healthcare